

# **THE LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM**

## **EDUCATION AND TREATMENT FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS**

### **Meeting the Need for Services among California's Children**

Based on parental reports in the California Health Interview Survey (CHIS), one study estimated that there are more than 36,000 children age three to 11 in California, nearly one percent of children age three to 11 statewide, who had autism in 2005. This represents a rate of autism of 7.8 per 1,000 California children age three to 11, an increase from 3.1 per 1,000 children in 2001.<sup>1</sup> This estimate would indicate that the rate of autism for California children age three to 11 more than doubled in less than five years. Recent national surveys focusing on school-aged children age four to 17 found prevalence rates of 5.7 per 1,000 and 5.5 per 1,000.<sup>2</sup>

Children with autism and autism spectrum disorders (ASD) and their families have varying needs for educational, health, mental health, and social services. Public and private services and funding sources are available to help families meet these needs. The primary sources of support for California families of children with ASD are the developmental services system, the educational system, and health insurance programs.

### **Developmental Services: Early Start and the Lanterman Act**

California's developmental services system is overseen by the California Department of Developmental Services (DDS) and implemented in the community by the 21 not-for-profit regional centers that contract with DDS to coordinate and purchase services and supports on behalf of eligible persons with developmental disabilities to help them live independent and productive lives. DDS also operates five developmental centers and two community facilities that care for persons who require programs, training, care, treatment, and supervision in a structured health facility setting on a 24-hour basis. Of persons served by DDS, most persons with autism live in the community and are served by regional centers.

#### **Early Start**

Young children under age three may receive early intervention services to meet their developmental needs through the Early Start program implemented by DDS and the regional centers in collaboration with the California Department of Education, local education agencies, and other state agencies. Pursuant to Part C of the federal Individuals with Disabilities Education Act (IDEA) and the California Early Intervention Services Act, Early Start serves California children that have a developmental delay or are at risk of delayed development or a developmental disability.<sup>3</sup>

Some of the services provided are screening and assessment; case management; speech, language, occupational and physical therapies; family counseling and training; vision and hearing services; and transportation services. Each child receives an individualized family services plan (IFSP) that specifies needed services for the family. Services are funded with

federal and state funds and provided at no cost to families, although private insurance may be used with the family's consent. Early Start Family Resource Centers throughout the state provide information and support to parents. More than 40,000 California children are served through Early Start annually. There is no data on how many of these children have the symptoms or diagnosis of ASD; the program does not collect diagnosis data since many children do not have an official diagnosis by age three.

### The Lanterman Developmental Disabilities Services Act

Children age three and older may be served through the developmental services system if they meet eligibility criteria specified in the state's Lanterman Developmental Disabilities Services Act. Persons are eligible for services if they have a substantial developmental disability that originates before age 18. State law defines autism as one of the disabilities that make a person eligible for services; mental retardation, epilepsy, cerebral palsy, and conditions similar to mental retardation are other diagnoses that render a person eligible for services. Persons diagnosed with some forms of ASD such as Asperger's syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDD, NOS) are eligible only if they have impairments that constitute a substantial disability, which is defined by California Code of Regulations Title 17 to be impairments in three of the seven areas of major life activity. Eligibility for persons with Asperger's syndrome and PDD, NOS is determined based on the person's functional ability.

Services may include care coordination, assessment and diagnosis, residential services, vocational services, day programs, respite, transportation, advocacy, and other services that support activities of daily living over a person's lifetime. Each consumer served by the regional centers has an individual program plan (IPP) that guides the purchase of services. With some limited exceptions where there is a family share of cost for certain services such as 24-hour out-of-home residential placement for children under 18, services are provided at no charge using federal and state funds. Regional centers are required to pursue generic resources provided by other public agencies and health insurance coverage when they are available and to provide services in the most cost efficient manner.

There are about 26,000 persons age three through 21 who are diagnosed with autism receiving services through the developmental services system.<sup>4</sup> In 2003-04, the average annual cost of providing services for this group was \$8,365 per person. In comparison, the average annual cost of services provided to persons age three through 21 who do not have autism was about \$5,800 per person.<sup>5</sup>

### **Education Services: Special Education and the IDEA**

California children age three through 22 may receive special education services through the educational system. Part B of the federal IDEA requires states and local education agencies (LEAs) to provide specialized instruction and related services to children with disabilities, including autism, in order to benefit from a free and appropriate public education (FAPE), and in the least restrictive environment. Services are provided at no cost to parents. Services are funded with a combination of federal, state, and local funds.

Federal and state laws do not prescribe specific educational entitlements for certain services. LEAs must evaluate a child's disability and needs for educational programming, develop an individualized education program (IEP) to meet that child's needs, and provide services according to the IEP. The IEP defines the type and amount of services that are appropriate based on a child's unique needs and is developed by a team, including parents, clinicians, district personnel, teachers, and other experts or advocates. Children may be educated in mainstream classrooms full-time or part-time, in specialized classrooms within the regular school, or in a specialized public or nonpublic school for children with special needs.<sup>6</sup> Placement in a nonpublic school or program may be financed by the LEA when it is determined that the LEA cannot offer the appropriate services for a FAPE. What constitutes a FAPE for students with disabilities is often debated and can lead to legal disputes between LEAs and parents.

Nearly 35,000 persons age three through 22 who have the primary diagnosis of autism receive special education services in California.<sup>7</sup> This is roughly 5 percent of pupils age three through 22 receiving special education services statewide. The costs to educate a California student with autism can range from \$25,000 to \$90,000 annually, according to one attorney specializing in autism and education law.<sup>8</sup> In comparison, it is estimated to cost about \$9,800 annually to educate the average special education pupil and about \$7,300 per year to educate the average pupil in a regular education classroom.<sup>9</sup>

## **Education and Treatment Approaches**

There is no known cure for ASD. Neither are there widely accepted, evidence-based, best practice guidelines for the education and treatment of persons with ASD. To fill this gap, DDS is currently convening a multidisciplinary group of experts to develop best practice guidelines for interventions for ASD. This state effort is being collaborated with a similar effort underway at the national level. In the meantime, parents have embraced a variety of treatment approaches, ranging from educational and behavioral interventions to biomedical approaches using medications, diets, and vitamins.

Some of the most common educational/behavioral approaches are Applied Behavior Analysis (ABA), which includes Lovaas, Pivotal Response Treatment (PRT), Discrete Trial Teaching, or Intensive Behavioral Intervention; Developmental, individual-difference, relationship-based (DIR), which is also known as Floor Time; Social Skills and Social Stories; TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children); speech-language therapy; sensory and occupational therapies; and communication strategies.<sup>10</sup> Of these approaches, ABA, including PRT, and Floor Time are the best known and most studied methods.<sup>11</sup>

There are few rigorously controlled studies of most approaches, and studies have produced mixed results with some children showing improvement and other children showing little or none.<sup>12</sup> It is not clear whether the approaches shown to have efficacy in controlled studies with highly trained clinicians are being used in typical community-based settings, what the barriers are to the use of these approaches, and if the techniques would produce similar results when

implemented in the community. There is evidence from one Southern California study that providers combine evidence-based and nonevidence based techniques, and few providers have a clear understanding of evidence-based practices.<sup>13</sup>

There is debate in the field about what is optimal. Without embracing any particular treatment, a national panel of autism experts concluded that children with ASD need early intervention for a minimum of 25 hours per week for 12 months per year, interventions should be cognitive-based and engage the child's social and emotional abilities, and parents should play an integral role in treatment.<sup>14,15</sup> Recent new investments in treatment research may shed more light on the effectiveness of approaches in coming years. Until then, there is a plethora of information on different approaches available to parents through publications and the Internet. There is a danger that parents could be misled by promises of cures and recovery without any scientific evidence to justify those claims.

## **Other Issues**

### Health Insurance Coverage

California's mental health parity law requires California health care plans and disability insurers to provide coverage for the diagnosis and medically necessary treatment of serious emotional disturbances of a child and severe mental illnesses of a person of any age. The law defines severe mental illness to include autism or pervasive developmental disorder.<sup>16</sup> It is unknown how this mandate translates into breadth of coverage for treatment since specific treatments are not mandated in law. National media and autism experts report that parents often battle insurers that deny coverage of autism treatments citing that treatments are experimental and not scientifically proven to be effective, not medically necessary, or provided by clinicians that lack qualifications and training.<sup>17</sup>

### Challenges Families Face in Navigating the Systems

There are reports that families experience problems and confusion when they transition from being served primarily by the Early Start program and the regional centers to the special education system when a child turns age three. The early intervention system and special education system are governed by different eligibility rules, requirements, processes, staff, service providers, cultures, and terminology. Parents need to reorient and train themselves about the new system. Parents may prefer that their child continue receiving the services he or she had received through the regional center vendors rather than what the LEA offers, which in some cases may be less intensive. Parents may file formal complaints against the LEA and/or the regional center for desired services. Collaboration between regional centers, LEAs, and parents can help ease the transition.

There are also frequent reports that families find the quality and quantity of educational services offered by LEAs for students with ASD very lacking, and some parents may not trust education professionals.<sup>18</sup> Observers indicate that federal and state special education funding has not kept pace with the rise in students with ASD. Problematic issues cited include inadequate funding for

services; pupil assessments that are not comprehensive (particularly for students with limited English proficiency); shortages of teachers, teacher aides and school psychologists; attrition of special education teachers; lack of evidence-based instructional strategies; little or no training for education professionals and paraprofessionals about ASD and how to teach to pupils with ASD; shortages of well-trained service providers to contract with LEAs and regional centers; and limited options for quality day care or after-school care.<sup>19</sup> Observers report that training on ASD is not a regular component of college and university training programs for educators, child care and early childhood providers, and other service providers, and as a result, these entities are unable to work effectively with the ASD population. This is seen as a major gap.

Parental dissatisfaction with LEA programs is evidenced by the dramatic increase in the number of formal complaints filed against LEAs for the education of students with ASD.<sup>20</sup> There has also been an increase in parents unilaterally placing children in private specialized schools and then billing the LEAs for reimbursement.<sup>21</sup> The process for resolving these disputes through administrative and court hearings is often costly, pitting the experts and attorneys of the LEAs against those of the families. Many disputes are resolved through private mediation.

In order to meet their federally mandated obligations to provide a FAPE to all pupils, LEAs may redirect funding provided for regular education to special education programs. It is unclear how other federal requirements on LEAs under the federal No Child Left Behind Act are affecting LEAs' ability to educate special needs pupils including students with ASD.

### **Identifying Gaps in State Policy**

There may be gaps in state policy related to the education and treatment of children with ASD. Consideration may be given to the following issues:

- Adequacy of pupils' needs assessments, including pupils of limited English proficiency;
- Lack of best practice guidelines for educational interventions and other treatments for ASD;
- Supply of regular education and special education teachers and teacher retention;
- Training for teachers, teacher aides, school psychologists, child care and early childhood education providers, and other service providers about ASD and how to effectively work with children with ASD;
- Availability and accessibility of well-trained service providers for ASD statewide;
- Standards for health care plan and disability insurance coverage of medically necessary treatment for children with ASD;
- Differences in eligibility, requirements, and processes between the developmental services system and the educational system and how they impact children's and families' access to services;

- Disputes between schools, regional centers, and parents regarding the education and treatment of children with ASD and the fiscal impact of dispute resolution; and
- Impact of federal requirements such as a FAPE to all pupils and those under the No Child Left Behind Act on the ability and efforts of schools to educate all students including those with ASD.

## Endnotes

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- <sup>3</sup> California Department of Developmental Services (DDS), *California Early Start Facts at a Glance*, Sacramento, California, January 20, 2005, available at <http://www.dds.ca.gov/earlystart>.
- <sup>4</sup> DDS, "Table #34, Client Characteristics at the End of June 2006, Autism," Sacramento, California, July 10, 2006, available at [http://www.dds.ca.gov/FactsStats/pdf/June06\\_Quarterly.pdf](http://www.dds.ca.gov/FactsStats/pdf/June06_Quarterly.pdf).
- <sup>5</sup> DDS, *Department of Developmental Services Fact Book, Eighth Edition*, Sacramento, California, December 2005, available at <http://www.dds.ca.gov/factsstats/factbook.cfm>.
- <sup>6</sup> Autism Society of America, *Building Our Future: Educating Students on the Autism Spectrum*, Bethesda, Maryland, 2006.
- <sup>7</sup> California Department of Education, "Special Education Enrollment by Age and Disability, Statewide Report," Sacramento, California, December 1, 2005, available at <http://data1.cde.ca.gov/dataquest/>.
- <sup>8</sup> Medscape Psychiatry and Mental Health, "Expert Interview: The Legal Rights of Children with Autism: An Expert Interview with Jill G. Escher," Medscape, 10(2), 2005.
- <sup>9</sup> Data provided by School Services of California, April 18, 2006, and August 31, 2006.
- <sup>10</sup> Autism Society of America, *Next Steps: A Guide for Families New to Autism*, Bethesda, Maryland, 2006.
- <sup>11</sup> The Brookings Institution and The Help Group, *Conference Report, Autism and Hope*, Washington, D.C., January 2006.
- <sup>12</sup> Carey, B., "Autism Therapies Still a Mystery, But Parents Take a Leap of Faith," *New York Times*, December 27, 2004.
- <sup>13</sup> Stahmer, A., Collings, N., and L. Palinkas, "Early Intervention Practices for Children with Autism: Descriptions from Community Providers," *Focus on Autism and Other Developmental Disabilities*, Summer 2005, 20(2): 66-79.
- <sup>14</sup> The Brookings Institution and The Help Group, *Conference Report, Autism and Hope*.
- <sup>15</sup> National Research Council, *Educating Children with Autism*, Committee on Educational Interventions for Children with Autism, National Academy of Sciences, Washington, D.C., 2001.
- <sup>16</sup> California Assembly Bill 88 (Thomson), Chapter 534, Statutes of 1999.
- <sup>17</sup> Freudenheim, M., "Battling Insurers Over Autism Treatment," *New York Times*, December 21, 2004.
- <sup>18</sup> Stoner, J., Bock, S., Thompson, J., Angell, M., Heyl, B., and E. Crowley, "Welcome to Our World: Parent Perceptions of Young Children with ASD and Education Professionals," *Focus on Autism and Other Developmental Disabilities*, Spring 2005, 20(1): 39-51.
- <sup>19</sup> Scheuermann, B., Webber, J., Boutot, E., and M. Goodwin, "Problems with Personnel Preparation in Autism Spectrum Disorders," *Focus on Autism and Other Developmental Disabilities*, Fall 2003, 18(3): 197-206; Weaver, B. and M. Hersey, "Issues and Trends in Treatment of Children with Autism Spectrum Disorders," available at <http://www.eparent.com/welcome/autism.htm>.
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